




Down Syndrome
Australia

A guide for new parents

Frequently Asked
Questions





This document has been produced by
Down Syndrome Australia.

Down Syndrome Australia is the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change, and provide a national profile and voice for people living with Down syndrome. We work collaboratively with the state and territory Down syndrome associations to achieve our mission. Our vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion.

Acknowledgements

Thank you to all of the people working and volunteering at the state and territory associations who have contributed to the development of this booklet.

The content of this booklet has been put together from the resources that the state and territory associations have developed over many years.

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Frequently asked questions and answers for new parents

Congratulations on the arrival of your new baby. This guide has been developed to help parents with some commonly asked questions that may arise in the first few weeks of your baby's life. Down Syndrome Australia has also developed a longer guide for new parents which is available at: www.downsyndrome.org.au

What is Down syndrome?

Down syndrome is a genetic condition. It is not an illness or disease. Our bodies are made up millions of cells. In each cell there are 46 chromosomes. Down syndrome is caused when there is an extra chromosome. People with Down syndrome have 47 chromosomes in their cells instead of 46. They have an extra chromosome 21, which is why Down syndrome is also sometimes known as trisomy 21.

Although we know how Down syndrome occurs, we do not yet know why it happens. Down syndrome occurs at conception, across all ethnic and social groups and to parents of all ages. It is nobody's fault. There is no cure and it does not go away.

More information about Down syndrome is available at www.downsyndrome.org.au/about-down-syndrome/



What can we do to help our baby reach their full potential?

Today, the future for children with Down syndrome is better than it has ever been before. Over the past 30 years or so, there have been big advances in health care, education and support services for people with Down syndrome, and a doubling of life expectancy in this period too. We've also seen huge shifts in the way the community views and treats people with disability. These days, people with Down syndrome can look forward to living long and fulfilling lives, with plenty of opportunities for making their own choices and living independently.

Your child with Down syndrome can and will learn. Sometimes we take children's development for granted. Children generally master skills like turning on a tap, learning to walk and remembering to say 'please'. Your child with Down syndrome will also master these kinds of skills but may need more time and support to do so.

As adults, some people with Down syndrome require minimal assistance to lead an ordinary life in the community, while others may require more support. Each person is unique, and the way they develop and reach their potential will depend on the individual.

Growth charts for children with Down syndrome can be downloaded from the [CDC website](#) (United States).

Know that your child will walk, will communicate, will learn and will grow to be an important part of their community, I can't stress that enough.

**PARENT OF A CHILD
WITH DOWN SYNDROME**

What will life be like for our family?

Many parents will worry about how a child with Down syndrome will affect their family. Of course, every family is different, but personal stories and research show that most families that have a child with Down syndrome are stable, successful and happy, and that their siblings often have greater compassion and empathy. Families generally find their feet and include the needs of their child with Down syndrome with the needs of all family members. How this happens will be different for everyone, because each child and family is unique.

Will I be able to breastfeed?

Although many babies with Down syndrome will quickly learn to breastfeed, some will take longer and need more help to get the hang of it.

All babies, including those with Down syndrome, are born with the instinctive knowledge and ability to get themselves to their mother's breast and to attach themselves correctly, with their mother's support. Spending one-on-one, skin-to-skin time with your baby when you are learning to put the baby to the breast will help to allow these 'baby-led attachment' instincts to work. It's also a lovely way to develop bonding between mother and baby.

The exercise of breastfeeding itself will improve your baby's muscle tone, and can help with speech and tongue control in the future and as with all babies, breast milk assists their immune system.

As your baby gets stronger and learns to breastfeed more effectively, they will be able to drink more milk. It is



important that you make sure your baby is getting enough milk. If you are having difficulty learning to breastfeed, we encourage you to employ the services of a skilled lactation consultant, or contact your local breastfeeding association. You can also express and bottle feed with breast milk, while your baby learns to feed. Remember that many mothers and babies need extra help to breastfeed.

The Australian Breastfeeding Association (ABA) has an information booklet called Breastfeeding: your baby with Down syndrome. This is available from www.breastfeeding.asn.au/bf-info/down-syndrome and Down syndrome associations.

Some babies with Down syndrome are not able to breastfeed. Don't worry if you find breastfeeding is not suitable for your baby. Sometimes low muscle tone causes difficulties with sucking or a medical problem may mean your baby is in hospital and the condition may make it difficult for your baby to breastfeed. Bottle-feeding is also a rewarding experience.

What health issues will my child have?

Many babies with Down syndrome are born without any health problems at all. However, some newborns with Down syndrome may experience some health concerns, such as:

- low muscle tone
- a heart defect
- digestive or feeding issues
- respiratory issues
- vision problems
- hearing difficulties
- obstructive sleep apnoea.

If your baby has a particular health concern, you will need to seek more specific and detailed information. Please talk to your health care professional about any of these medical matters, and ask for information as you need it.

What support is available?

You can get a range of support from different places. Initially, hospital staff are there to help. They will provide you with advice and ongoing care for any health needs your baby may have. There is also general health information about Down syndrome in the Guide for New Parents, available at www.downsyndrome.org.au/resources/life-stages/new-parent/.

Don't hesitate to ask for more information or advice from your health care professionals.

Another source of support that you may like to consider – either now or further down the track – is talking to other parents of children with Down syndrome. No one else will understand what you are going through quite as well as they do. Your experience is unique, but these parents are very familiar with how it feels and the questions you will have when you have a new baby with Down syndrome.

The Down syndrome association in your state and territory are the experts on Down syndrome and they can support you or put you in touch with local families. Links to your local association can be found at www.downsyndrome.org.au/about-us/our-federation/.

There is also a range of professional support services available, including speaking to a counsellor or mental health professional. You can ask your family doctor, the hospital staff or the Child and Health Services in your area to point you in the right directions. Your local Down syndrome association can also assist you to find the right services when the time is right.

Try to have a bit of time for yourself when you can. It's important for your health and wellbeing and will help your family too.



NDIS support

The NDIS have developed an Early Childhood Early Intervention (ECEI) approach to provide support to children who will benefit from early intervention.

Children with Down syndrome who are under the age of 7 are eligible for these supports if they meet Australian residency requirements. Down syndrome is included in 'List D' which is a list of conditions which require no further assessment for access to the scheme.

The Early Childhood Early Intervention organisation will work with your family to develop a plan for therapy and support that focuses on goals that relate to the child's age, development and social skills.

Find out more about Early Childhood Early intervention on the NDIS website: www.ndis.gov.au/understanding/families-and-carers/how-ecei-works-step-step-process

Find an Early Childhood partner in your area: www.ndis.gov.au/contact/locations

You can also get in touch with your local Down syndrome organisation to get more information and support about applying for NDIS.



Associations

National: 1300 881 935

New South Wales

Down Syndrome NSW

T: 1300 881 935

E: admin@dsansw.org.au

W: www.downsyndrome.org.au/nsw

Victoria

Down Syndrome Victoria

T: (03) 9486 9600

Toll Free 1300 658 873

E: info@dsav.asn.au

W: www.downsyndrome.org.au/vic

Queensland

Down Syndrome Queensland

T: (07) 3356 6655

E: office@downsyndromeqld.org.au

W: www.downsyndrome.org.au/qld

South Australia

Information Service South Australia (Down Syndrome Australia)

T: 1300 344 954

E: infoSA@downsyndrome.org.au

W: www.downsyndrome.org.au/sa

Western Australia

Down Syndrome WA

T: (08) 6253 4752

E: admin@downsyndromewa.org.au W:

www.downsyndrome.org.au/wa

Tasmania

Down Syndrome Tasmania Inc.

T: 1300 592 050

E: info@downsyndrometasmania.org.au

W: www.downsyndrome.org.au/tas

Northern Territory

Down Syndrome Association NT

T: (08) 8985 6222

W: www.downsyndroment.com.au

Australian Capital Territory

ACT Down Syndrome Association Inc.

T: (02) 6290 0656

E: admin@actdsa.org.au

W: www.downsyndrome.org.au/act



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